

## Retaining and Tracking Cohort Study Members

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### INTRODUCTION

Retaining and tracking cohort participants is crucial for "longitudinal" cohort studies, i.e., those that require periodic contact with participants after cohort entry to update exposures and/or ascertain outcome events. A major effort in such studies will be devoted to follow-up, one of the greatest challenges to the success of a longitudinal cohort study. While even well-designed studies will have some loss to follow-up, there are several strategies and activities that can be undertaken to keep the loss to a minimum.

Loss to follow-up may occur because the participant has decided that he/she no longer wishes to participate (drop outs) or because the study investigator has lost track of the participant. Maintaining contact with cohort study participants is crucial, as there is some evidence to suggest that lost participants may differ more from participants who respond than participants who can be found but refuse to respond (1). Thus, locating lost participants may be as, or more, important in minimizing bias as obtaining a high response rate in those who are easily found. Of particular concern is that those who cannot be found may be lost to follow-up because they have developed the disease outcome of the study or have died. These types of losses lead to reduced study power and may lead to bias in the odds ratio (2, 3). Therefore, every effort should be made to encourage participation of, and contact with, all cohort members until the end of the study. Methods to maximize retention and keep track of cohort members, use of proxies to collect follow-up data, and procedures for locating hard-to-find or "lost" participants are discussed in this presentation. Although our focus is on participants in longitudinal cohort studies, the section on Tracing hard to find or lost participants, below, may also apply to tracking participants in retrospective cohort studies.

### STRATEGIES TO MAXIMIZE RETENTION AND MINIMIZE NONRESPONSE

Retention of study participants is the primary focus of activity following enrollment in a longitudinal cohort study. Cohort studies have used a range of strategies and procedures to assure a participant's retention throughout the course of the study, from initial screening to the last follow-up contact. Choice of strategy is driven by many factors, including length of follow-up, cost, and study population of interest. Most of the strategies described below are for use when following members of the general population, as opposed to the more difficult to reach segments of society such as intravenous drug users or homeless teenagers. While most of the procedures can be adapted for many different types of study populations, special procedures for enrolling, following, and tracing hard-to-reach or "high risk" members of the population may be necessary (4-6).

To help illustrate the types of retention strategies used, we identified four longitudinal studies that provided sufficient detail of their procedures: the Multi-center AIDS Cohort Study (7), the Nurses' Health Study (8), the Women's Health Initiative Clinical Trial and Observational Study (9), and the St. Louis Effort to Reduce the Spread of AIDS (ERSA) study (4); an overview of their retention strategies is presented in table 1. These studies involve follow-up of four different populations: men at risk for human immunodeficiency virus (HIV), registered nurses, postmenopausal women, and intravenous drug abusers. The strategies used by these studies, and others, are based on a combination of empirically supported techniques, experience, and intuition. While there are many similarities in the follow-up procedures shown in table 1 (i.e., additional mailings and telephone calls to nonresponders; collection of extensive information at baseline to enhance ability to track hard-to-find participants; use of the US Postal Service, telephone directories, and the National Death Index to search for lost participants), differences can be noted when comparing procedures for tracking members of the general population (e.g., postmenopausal women) versus those of hard-to-reach members of society (e.g., drug users).

Received for publication July 18, 1997, and accepted for publication April 1, 1998.

Abbreviations: NCOA, National Change of Address system.

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**TABLE 1. Methods used to maximize retention in four cohort studies: The Multicenter AIDS\* Cohort Study, The Nurses' Health Study, The Women's Health Initiative Observational Study, and The St. Louis Effort to Reduce the Spread of AIDS Study*****The Multicenter AIDS Cohort Study (7)****Design and population.*

A longitudinal, multicenter study of 4,954 men to observe the natural history of HIV-1\* among homosexual and bisexual men

*Length of follow-up*

9.5 years (April 1984–September 1993)

*Enrollment, consent, and baseline activities*

- Participants were recruited at four centers through notices placed in gay bars, newspapers, and community centers
- Participants were enrolled during a clinic visit consisting of physical examination, blood draw, and questionnaire completion
- At enrollment, participants provided Social Security number, driver's license number, names and addresses of two people who would always know how to contact them, and name of physician
- Participants signed consent to the release of medical records

*Follow-up procedures and intervals*

- Participants reexamined at clinic at 6-month intervals
- At each visit, participants are encouraged to make appointment for next visit
- Reminder letter sent 2–4 weeks before appointment
- 2 weeks after letter, telephone contacts are initiated until participant is reached to confirm appointment

*Extra efforts to minimize nonresponse*

- If full participation is not feasible, men can respond to a short mailed questionnaire to collect primary outcomes and vital status
- After 3 weeks, nonresponders are interviewed by telephone
- Quarterly telephone contact is maintained with those too ill to visit study site
- Home visits are made when possible
- If participants move outside of clinic area, they are given a blood kit that their own physician can use to obtain blood specimens, which is then shipped to the laboratory. Interview is conducted by telephone

*Tracing hard to find and lost participants*

- Extended search is initiated for those who cannot be reached
- Postal services, such as registered mail, address correction, and mail forwarding, are used
- Search includes: contacts named by participant, county and state death certificates, obituaries, AIDS-registries, the National Death Index, departments of motor vehicles, consumer information services, and tax and voters lists

*Success rate*

At 9.5 years, AIDS and/or vital status was known for 89% of cohort

***The Nurses' Health Study (8)****Design and population*

A longitudinal study of a cohort of 121,700 registered nurses to examine the relation between contraception and breast cancer; later expanded to include diet and other exposures and outcomes

*Length of follow-up*

Women enrolled in 1976; 20 year follow-up conducted in 1996

*Enrollment, consent, and baseline activities*

- Participants were registered nurses recruited by mail via an introductory letter, two-page questionnaire, and prepaid return envelope
- Information collected at baseline to assist in tracking included the participant's name, Social Security number, birthdate, and the name, address, and phone number of a personal contact

*Follow-up procedures and intervals*

- Follow-up questionnaires are mailed to all cohort members every 2 years
- Questionnaires are mailed with a cover and a newsletter updating participants on study progress
- Personal contacts are identified by study members every 4 years
- First questionnaire is mailed in June; second mailing is sent to nonresponders in September
- Third and fourth mailings with full questionnaire are sent to nonresponders
- Fifth mailing of short version questionnaire with key exposure variables and outcomes is sent to nonresponders
- Newsletter with study updates is included in fifth mailing

*Extra efforts to minimize nonresponse*

- A telephone follow-up to nonresponders (to the five mailings) was added in 1982
- Additional approaches were added in 1986, including sending questionnaires by United Parcel Service and certified mail
- In 1990, used both telephone and certified mail to reach nonresponders from earlier years

Table continues

TABLE 1. Continued

*Tracing hard to find and lost participants*

- Women are traced through the local postmaster, state boards of nursing, and personal contacts listed by participants
- Deaths are reported by participant's next of kin or by postal authorities
- National Death Index is searched for deaths among nonrespondents

*Success rate*

Using the combined approaches since 1990, responses have been received from over 90% of cohort

***The Women's Health Initiative Observational Study (9)****Design and population*

A longitudinal, multicenter study of 100,000 postmenopausal women to examine the relationship between lifestyle, health and risk factors, and specific disease outcomes

*Length of follow-up*

Women enrolled 1994–1998; follow-up for 8–12 years (depending on year of enrollment)

*Enrollment, consent, and baseline activities*

- Participants were enrolled during a clinic visit consisting of physical examination, blood draw, physical measures, and questionnaire completion
- At baseline, participant tracking information was collected, including Social Security number, birthdate, the names, addresses, and phone numbers of at least two personal contacts, and physician's name

*Follow-up procedures and intervals*

- Mailed questionnaire with cover letter is sent annually
- Reminder/thank you postcard is sent 1 month later
- Second full questionnaire and cover letter is sent 3 months after first questionnaire to nonresponders
- Third full questionnaire and cover letter is sent 5 months after first questionnaire to nonresponders
- Participants are reexamined at clinic 3 years after enrollment
- Telephone and/or mailed reminders are made during the month before the visit
- Small incentive item, with study logo, is provided during visit
- Study newsletters are sent to all participants annually at 6 months post-enrollment month
- Birthday and holiday cards are sent annually by some clinic sites
- Personal contacts are identified by study members every 3 years

*Extra efforts to minimize nonresponse*

- Telephone contacts to nonresponders are made every other year to collect data on key variables and primary outcomes
- Proxy interviews to collect primary outcomes are conducted if participant is deceased or has diminished cognitive functioning

*Tracing hard to find and lost participants*

- Search is initiated to trace participants who cannot be located, including contact with personal contacts and physician
- National Death Index is searched to determine vital status of those lost to follow-up

*Success rate*

Study in progress—responses to date to the first annual mail and telephone follow-up were received from 95% of those due

***The St. Louis Effort to Reduce the Spread of AIDS Study (4)****Design and population*

A cohort study of 479 intravenous drug-users designed to reduce the spread of HIV among St. Louis' drug-using population while improving drug abuse treatment

*Length of follow-up*

Participants were followed for 18 months

*Enrollment, consent, and baseline activities*

- Participants were enrolled by street outreach workers
- Baseline assessment included psychiatric illness, high risk behavior, and treatment response
- At baseline, participant tracking information was collected, including legal name, nicknames and aliases, best mailing address, mother's and father's full names, Social Security number, birthdate, the name, address, and phone number of lawyer, probation officer, or parole officer, if any
- Informed consent guaranteed confidentiality of data
- Drug treatment was made available to those interested

Table continues

TABLE 1. Continued

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*Follow-up procedures and intervals*

- Participants were interviewed 3, 6, 9, 12, and 18 months post-baseline to determine changes in behavior; blood drawn at baseline and 12 months
- Reminder letters were sent to each participant that an interview will soon be scheduled
- Once the participant was reached, an interview appointment was scheduled

*Extra efforts to minimize nonresponse*

- Additional contacts were made by a refusal converter to persuade participants refusing to be interviewed at follow-up
- Participants were compensated with supermarket food gift certificates (various denominations for each task and bonuses provided for completion of all waves)

*Tracing hard to find and lost participants*

- Study 'trackers' used a three-stage tracking system: phone, systems, and field
- Phone tracking included search of telephone books, directory assistance, Haines Criss-Cross directories
- Systems tracking included credit agencies, various state and local agencies, hospitals, treatment programs, prisons, welfare agencies, voter registration, and department of motor vehicles
- Field tracking included visits to participant's and neighbor's homes and "allegedly frequented" hangouts (e.g., bars, pool halls, barber, street corners)
- Conducted weekly team meetings to coordinate tracking efforts

*Success rate*

At 18 month follow-up, 455 of the 470 participants still alive were located and interviewed (96.8%)

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\* AIDS, acquired immunodeficiency syndrome; HIV, human immunodeficiency virus.

A summary of the general strategies to maximize retention described below are summarized in table 2.

### Enrollment, consent, and baseline activities

Retention begins during recruitment, even during the first contacts with potential study participants. Before enrollment into the study, potential participants should be assessed for their willingness to participate. If they seem hesitant to participate or their future

cooperation is at all questionable, they should not be enrolled. (This assumes that the response bias due to losses at baseline is generally less than the response bias due to failure to follow-up all enrollees, because the former is less likely to be jointly influenced by exposure and [future] disease occurrence than the latter.) Also, before enrollment, participants should be required to complete the types of tasks that will be required during the follow-up phase, similar to a "run

TABLE 2. General strategies to maximize retention

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*Enrollment, consent, and baseline activities*

- Screen potential participants for willingness to participate over the long-term
- Have participants complete set of tasks at baseline before enrollment
- Fully inform participants of commitment and requirements of study
- Collect participant tracing information, such as address, phone number, Social Security number, date and place of birth
- Collect names of personal contacts and proxies

*Bonding*

- Create study logo and theme
- Send newsletters, holiday cards, and study updates

*Frequency of contact*

- Regular contacts with participant, at least every 6–24 months
- Strive to collect primary outcomes, at a minimum
- Use tracking system to monitor follow-up activities

*Staff characteristics*

- Well trained and enthusiastic
- Open communication
- Respond promptly to questions or problems
- Scheduling flexibility

*Incentives*

- Small tokens of appreciation with study logo
- Regular feedback of information and study progress
- Cash for mailed surveys

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in" phase before randomization in a clinical trial. For example, if the participant is expected to complete surveys or diaries or come in for a physical examination, these tasks should be part of the baseline requirements. Investigators should not continue to reschedule no-shows or allow multiple attempts to enroll the participant. If it is difficult to get the participant to complete the tasks at baseline, it may be impossible to get him or her to participate during the follow-up period.

During the enrollment period, it is very important to clearly communicate expectations of participation, including the frequency, duration, and number of follow-up visits or contacts that will occur. Sharing these expectations helps participants make an informed decision about participation. For example, in the Women's Health Initiative, a 12 year observational study of 100,000 women, expectations of participation, including a physical examination and blood drawn at baseline, completion of annual questionnaires, and a follow-up clinic visit at year 3, were clearly reviewed with cohort members during the consent process (10). Enrollment did not occur unless all baseline tasks were completed.

#### **Collecting baseline information to minimize loss-to-follow-up**

Longitudinal studies generally require collection of information at baseline that will help the investigator locate lost participants, or, at the very least, determine their vital status. Useful items include the names and addresses of at least two friends or relatives not living with the participant who are likely to know his or her whereabouts, the participant's birthdate and Social Security number, the name under which the participant's telephone is listed, and the names of family members and health care providers who may be able to serve as a proxy respondent in the event of the participant's death. Additional items that may enhance the success of searching the National Death Index to determine vital status of lost cohort members are summarized in a later section of this presentation. As shown in table 1, the type of information collected for tracking purposes varies across studies, determined in part by the study population. For example, in the St. Louis Effort to Reduce the Spread of AIDS study (4), information not typically collected, such as aliases and the names, addresses, and telephone numbers of lawyers and parole and probation officers, was obtained at baseline.

#### **Frequency of contact**

Once a participant has been enrolled, frequent personal and mail contact with participants should be

maintained. The frequency of follow-up contact in most longitudinal epidemiologic studies has generally been in the range of 6–24 months. While this depends on the frequency needed to collect accurate exposure and outcome data, generally contact every 6–12 months is needed to maintain current addresses. Because the US Postal Service generally keeps change of address records for 6 months only, contact should ideally occur at least every 6 months to obtain up-to-date address information, as well as to maintain interest in the study and remind the participant that he/she is a cohort member.

The study investigator should, at least annually, try to contact participants who have dropped out of the study in an attempt to collect primary outcomes and/or to get them to rejoin the study. The personal information collected at baseline, especially information about friends or relatives who will know the participant's whereabouts, will help trace participants who cannot be initially located and should, therefore, be updated periodically.

When cohort members are reluctant to continue with full participation during the follow-up period, collection from the participant of information on the primary outcomes of interest should be continued, at a minimum. In the Oxford Family Planning Association contraceptive study, a cohort of 17,000 women received annual clinic follow-up examinations for 10 years. Women who stopped attending the clinic were sent a mailed questionnaire annually and, when this was not returned, were interviewed by telephone or during a home visit in an attempt to collect data on several of the primary outcomes (11).

#### **Staff characteristics**

Selection, training, and supervision of staff and data collectors are important parts of maintaining participation in longitudinal studies. Staff members must have skills that enhance the participant's desire to participate, reflect the importance of the study, and demonstrate enthusiasm and commitment to the project (12). These skills may help reduce participants' reluctance to continue in the long-term and encourage accuracy in their responses (13, 14). In a study evaluating factors encouraging retention in the Framingham Children's Study, Marmor et al. (15) found that staff characteristics, including their attitudes, responses to questions and problems, and scheduling flexibility, to be among the factors most important in keeping participants in the study.

#### **Bonding**

Participants in a longitudinal study need to identify and bond with the study and become committed to

active involvement. Given et al. (12) suggest creation of a study logo and theme and use of these in letters, envelopes, questionnaires, newsletters, and other communications to establish a connection with the study. Continuity of contact between participants and study investigators will enhance bonding and help ensure ongoing identification with the study. Newsletters, holiday cards, and updates on study progress have been used as bonding tools, as well as to provide an opportunity to obtain updated address correction information from the US Postal Service through use of a "Change Service Requested" instruction on the mailed piece (8, 16).

### Community advisory boards

The formation of community advisory boards, consisting, for example, of health professionals, members of the population being studied, members of the business community, and other prominent community members, can provide a link between study investigators, the study population, and the community at large. Advisory boards may serve many valuable functions and help solve retention problems, such as identifying and providing transportation options or soliciting incentive items from local merchants. Including participant representatives on the board may also help promote bonding and long-term study participation. Representatives can provide the participant's perspective on study activities and may be able to help identify barriers to retention.

### Incentives

Providing incentives, especially those that are linked to the tasks of the study (for example, a pocket calendar to keep track of medical events) may enhance retention, as well as help with the collection of outcomes (17). Incentives may also be effective when something additional is being asked of the participant (e.g., completion of a diary or submission to some form of physical examination or test) (18). In the Framingham Children's Study, periodic updates on study results and results of cholesterol screening tests were found to be successful incentives for encouraging participation (15). Incentives are often used in longitudinal studies to express appreciation for the participant's involvement, and mementos and gifts remind participants of their participation throughout the year. In the Family Caregiver's Study, participants were given coffee mugs, desk calendars, clocks, and ballpoint pens embossed with the study's logo (12). For hard-to-reach study populations (e.g., drug abusers, prostitutes), the type (e.g., food certificates, free health

care) and amount of incentives can be central to retaining and tracking cohort members (19).

For mailed surveys, the most effective incentive appears to be something enclosed with the letter, usually cash (20–23). There is evidence that final response rates may be just as high if the incentive is enclosed only with later mailings to nonrespondents, which may lead to cost savings (22).

### Tracking systems

Using some type of tracking system for monitoring follow-up activities is essential (24). A successful system will enhance study efficiency, and perhaps overall response, by providing an organizational framework to help keep track of activities. When designing a tracking system, study needs, length, resources, and cohort size should be taken into consideration. Tracking systems vary from simple paper logs of follow-up phone calls to elaborate computer-based systems that track every aspect of participation, from baseline participant information to final follow-up contact. Several software packages used for tracking, called "workgroup contact managers", are available on the market (25, 26). While new packages are continually being developed, examples of Windows-based contact managers currently available include GoldMine (Elan Software Corporation, Pacific Palisades, CA), Maximizer (Modatech Systems International, Dallas, TX), Tracker (Tracker Software, Inc., Minneapolis, MN), and ACT! (Symantec Corporation, Cupertino, CA). Computer-based tracking systems to fit the individual tracking and monitoring needs of most studies can also be developed by using database packages. Examples of two database software packages available on the market are FoxPro and Access for Windows (both from Microsoft Corporation, Redmond, WA); these are relational database managers that operate on IBM-compatible computers.

A tracking system may be used for multiple purposes, such as allowing study investigators to:

- Track participant's current participation status (e.g., refuses contact; location unknown, etc.);
- Access and update contact information on the participant and his/her proxies, relatives, friends, and health care providers;
- Schedule follow-up activities, such as annual mailings or appointment reminders;
- Track responses to follow-up contacts and completion rates;
- Automatically produce letters or forms (e.g., appointment reminders);
- Generate reports that prompt follow-up activity (e.g., a list of participants needing telephone follow-up due to nonresponse to a mailed survey);

TABLE 3. Examples of tasks included in a cohort participant tracking system

Participant contact information	Scheduling and monitoring task completion	Reports generated	Forms and materials generated
<ul style="list-style-type: none"> <li>• Full name</li> <li>• Nicknames</li> <li>• Enrollment date</li> <li>• Date for annual follow-ups</li> <li>• Current participation status</li> <li>• Birthdate</li> <li>• Place of birth</li> <li>• Sex</li> <li>• Race</li> <li>• Marital status</li> <li>• Social Security no.</li> <li>• Driver's license no.</li> <li>• Home phone no.</li> <li>• Work phone no.</li> <li>• Other phone no.</li> <li>• Address</li> <li>• Employer information</li> <li>• Spouse contact information</li> <li>• Information on mother</li> <li>• Information on father</li> <li>• Other friends/relatives contact information</li> <li>• Physician contact information</li> </ul>	<p>Scheduling prompts</p> <ul style="list-style-type: none"> <li>• Due for visit</li> <li>• Past due for visit</li> <li>• Due for annual mailing</li> <li>• Past due for annual mailing</li> </ul> <p>Routine visits completed</p> <ul style="list-style-type: none"> <li>• First annual visit</li> <li>• Second annual visit</li> <li>• Third annual visit, etc.</li> </ul> <p>Mailed data collection</p> <ul style="list-style-type: none"> <li>• Response to first annual mailing received</li> <li>• Response to second annual mailing received</li> <li>• Response to third annual mailing received, etc.</li> </ul> <p>Summaries</p> <ul style="list-style-type: none"> <li>• % completed first visit</li> <li>• % completed mail surveys</li> </ul>	<ul style="list-style-type: none"> <li>• Participants with undeliverable or problematic address in database</li> <li>• Participants requiring search (current location is not known or invalid)</li> <li>• Participants needing follow-up phone calls due to non-response to mailing</li> <li>• Participants to schedule this week for annual appointments due next month</li> <li>• Participants needing phone calls this week due to recent appointment no-show</li> <li>• Participants with incomplete questionnaire data</li> </ul>	<ul style="list-style-type: none"> <li>• Labels for annual questionnaire mailing</li> <li>• Thank you/reminder postcards</li> <li>• Labels for nonresponders needing follow-up mailings</li> <li>• Labels to send annual newsletter</li> <li>• Postcards for appointment reminders</li> <li>• Labels for those needing birthday cards this month</li> </ul>

- Generate mailing labels with the most up-to-date address;
- Track results of activities to search for participants who cannot be located; and
- Provide statistical summaries of response rates.

Table 3 provides an example of the types of reports, materials, participant tasks, and staff activities that can be tracked, generated, and monitored with a computerized tracking system.

### ENHANCING RESPONSE RATES FOR VARIOUS DATA COLLECTION METHODS

A major challenge of longitudinal cohort studies is maximizing the response rate at each data collection point. The following discussion focuses on the three major types of data collection methods: mailed survey, telephone interview, and in-person interview, including clinic visits. Although many of the strategies discussed are based on research on enhancing initial recruitment rates, most of the recommendations may also hold for increasing the response rates of cohort members who already have been recruited and agreed to participate. Factors that may increase response rates for each of the three methods of data collection are summarized in table 4.

#### Mail surveys

A large number of approaches for follow-up by mail surveys that may increase response rates have been discussed by Kanuk and Berenson (27), Linsky (20), Dillman (28), Baumgartner and Heberlein (21), Fox et al. (29), and Armstrong et al. (30).

**Cover letter.** Findings from the Hypertension Prevention Trial found that a higher response rate to a recruitment mailing was achieved when a cover letter and brochure were included in the mailing versus sending a brochure alone (31). Elements to include in a cover letter requesting follow-up data from cohort members are: a reminder of what the study is about and who the sponsor is, a statement of why the participant is important to the study, a promise of confidentiality, reference to the incentive, a statement of what to do if questions arise, and an expression of appreciation. In second and third mailings to nonresponders, the cover letter should include similar elements along with an additional reminder that the response has still not been received and that participation is very important.

**Questionnaire.** Dillman (28) suggests that questionnaires be printed on both sides of the paper, and in booklet form, for ease of use. While research shows that the length of the questionnaire, up to about 12 pages, does not impact response rates, Dillman recommends that questionnaires be printed with reduction to  $8\frac{1}{4} \times 6\frac{1}{8}$  inches so that they appear to be small (28). Regardless of paper size, the questionnaire should not look crowded and should have a font size that is easy to read.

**Outside envelope.** The use of hand-addressed envelopes was found to significantly increase the rate of response from cohort members in the Health Professionals Follow-up Study who had not responded to three previous mailings (32). There is also some evidence that using commemorative or multiple small denomination stamps on the outer mailing envelope

**TABLE 4. Factors that may increase response rates in mail, telephone, and in-person interviews**

<i>Mail surveys</i>	
Advance notice that a questionnaire will be sent	
Cover letter explaining importance of participation	
Government or University sponsorship	
Personalization of correspondence	
A handwritten address	
Small format questionnaire	
An incentive included with the questionnaire	
Stamped return envelope	
Special class (e.g., certified) mailings to nonresponders	
Commemorative stamps on outward mailing	
Requesting address correction on the mailing envelope	
Multiple mailings	
Inclusion of a questionnaire with mailings to nonresponders	
Telephone or in-person follow-up to interview nonresponders	
<i>Telephone interviews</i>	
Advance letter	
Experienced interviewers who sound confident and competent	
Use of most effective interviewers to contact reluctant responders	
Personalized and carefully constructed introduction	
Multiple attempts to contact at a variety of times	
Mailings or home visits for nonresponders	
<i>In-person interviews and clinic visits</i>	
Advance letter	
Careful selection and training of interviewers	
Convenient appointment times	
Appointment reminders	
Free parking or transportation provided	
Multiple attempts at contact	
Mail or telephone contact for nonresponders	

increases response rates (33). At a minimum, the study's name or logo should appear on the outer envelope so as to be recognizable to the study participant.

In order to keep address information up-to-date, outer mailing envelopes should be printed with "Change Service Requested" below the study's return address in the upper left-hand corner. For a minimal fee per mailpiece, the US Postal Service will supply the study investigator with updated address information.

**Return envelope.** Using a stamped return envelope, as compared with a "business reply paid" envelope, has been shown to result in higher response rates (34). While this can be quite costly for initial recruitment mailings, it is generally cost-effective in cohort follow-up mailings when response rates are expected to be high.

**Mailing schedule.** Several studies have shown that probably the most important strategy for increasing response rates in mail surveys is the use of multiple mailings (20, 21, 27–29, 32). Dillman (28) recommends the following strategy as part of his "total design method":

Mail initial questionnaire;

One week after the questionnaire is mailed, send a postcard to all participants to thank those who have responded already and to remind those who have not.

Mail a follow-up letter to nonrespondents 3 weeks after the initial mailing. This letter informs them that their questionnaire has not been received and re-states the importance of their response.

Send a second follow-up letter and copy of the questionnaire to nonrespondents, by certified mail, 7 weeks after the first mailing.

The timing and number of these mailings should be tailored to fit the individual study. For example, when sending a large number of mailings using bulk or third class mail, an adequate length of time between mailings is needed to ensure that respondents have enough time to receive and return their surveys.

**Special class mailings.** Several studies have shown that certified and first-class mail yield the highest response rates, as compared with lower class or bulk rate mail (21, 29). In a study comparing various mailing strategies to contact 12,233 cohort members of the Health Professionals Follow-up Study who had not responded to three successive bulk-rate mailings, Rimm et al. (32) found that response rates were highest from those participants who were sent a certified mailing. Although altering the physical appearance of the envelope and using other postal rates were tested, certified mail was the most effective approach of obtaining responses from former nonresponders, presumably due to the perceived importance of certified mail compared with other types of mail. If a return receipt is requested (which is more expensive and should probably be used only when all other attempts have failed), the investigator can also verify that the mailing was actually received by the participant.

**Telephone or home visit for nonresponders to mailed questionnaires.** Response rates may be increased substantially if additional methods are used to try to contact initial nonresponders (35). Several longitudinal cohort studies have used a combination of mailed questionnaires with additional telephone or in-person contacts to nonresponders to maximize response. For example, the Alameda County Study, a longitudinal cohort study that has followed the physical health and well-being of a population sample of a California county for nearly 30 years, uses data collection procedures that consist of an initial mailing, followed by repeated contact of nonresponders by mail, telephone, and in-person contact (36). The initial contact by mail, followed by two additional mailings, resulted in a response rate of 81 percent; follow-up by telephone or home visit increased the response rate to 88 percent. In the Washington County, Maryland, co-



hort study, 93 percent of the participants interviewed in 1978 were successfully traced and sent a mailed questionnaire in 1995. Those participants who did not return their questionnaire after two mailings were contacted and interviewed by telephone, resulting in a 90 percent response rate (37).

A study by Battistutta et al. (38) suggests that telephone or home visit contacts that serve merely as reminders are unlikely to be effective in increasing response rates and so, when contact is made, the questionnaire should be completed by an interviewer at that time.

### Telephone interviews

Factors that may increase response rates in telephone surveys have been reviewed by Dillman (28), Groves and Lyberg (39), and Armstrong et al. (30), and are summarized in table 4.

*Advance warning or letter.* As with any type of follow-up data collection, the participant should be given advance warning during the enrollment/recruitment phase of the project that periodic telephone interviews will occur. A mailed reminder before the telephone call occurs may help reduce the element of surprise and may increase the response (18, 40).

*Interviewers.* Oksenberg and Cannell (41) found evidence to suggest that better response rates are obtained by interviewers who are perceived as sounding confident and competent (i.e., by speaking rapidly, loudly, and with standard pronunciation) than by those who do not. In addition, callbacks by another, usually more experienced, interviewer to participants who initially refuse to provide follow-up data may result in responses.

*Carefully constructed introduction.* Because most refusals occur during the introduction, including carefully worded and relevant information at the beginning of the call is important. Dillman (28) recommends that the introduction should ascertain that the correct telephone number and person have been reached, inform the participant of the purpose of the call, remind him/her of the purpose of the study and the importance of his/her contribution, and give the expected duration of the interview. When a proxy respondent is being interviewed following the death or illness of the cohort participant, carefully worded scripts should be provided for interviewers.

*Timing and number of calls.* Several attempts may be necessary to obtain a completed interview by phone; interviewers should not give up on trying to reach a participant until at least 12–15 attempts have been made (42). Attempts to reach the participant should be made both in the evening and during weekends and again after several weeks. Careful record-

keeping of calling attempts will allow for periodic review and possible revision of the call strategy.

*Mailings or home visits for nonresponders.* Response rates to telephone surveys can be increased by a mailing or home visit, if contact is not established by telephone. Respondents not reached by telephone may be willing to complete a mailed questionnaire or in-person interview; attempting contact by either or both of these methods may also provide information about the reason for noncontact by telephone (e.g., participant has moved to a new location) that can help lead to later contact. In research conducted at the Alameda County Human Population Laboratory, Hochstim (35) observed that adding mail follow-up to nonrespondents to the initial telephone interview increased response rates from 86 to 91 percent.

### In-person interviews and clinic visits

In-person data collection may occur at a variety of locations, including the cohort member's home or workplace, or at the study clinic itself in the case where procedures or specimens, such as blood collection, are required. Several of the principles outlined above for telephone interviews can be applied to in-person interviews; additional suggestions follow.

*Convenience of the appointment.* A variety of times and days for the appointment or interview, including evenings and weekends, should be made available to the participant. When appointments have been set up weeks or months in advance, a call or letter should be used to remind the participant of the appointment. When the participant is required to keep an appointment at the study site, free, convenient parking should be provided. Thorough directions and clearly marked signs are crucial. It may also be necessary to provide transportation (e.g., a study van or bus tickets) for some study participants.

*Mail or telephone contact with nonresponders.* Some participants will refuse study visits, be unable to participate in visits due to health or a move out of the area, or not show up even after appointments have been rescheduled several times. In these situations, collection of data, particularly that pertaining to primary outcomes, should be attempted by mail or telephone.

### USE OF PROXIES TO OBTAIN FOLLOW-UP INFORMATION

Proxy or surrogate respondents are often used to provide information about study participants who are unable to continue to participate due to death, illness, or dementia. When cohort participants are enrolled in the study, it is important to obtain consent to interview

proxies in the event that the participant is unable to provide data at some point. During enrollment, the participant should be asked to provide the names of several relatives, close friends, and physician(s) from whom proxy information can be sought. Any required medical release forms should also be completed at the onset of the study to aid in the procurement of information related to medical outcomes.

Missing data (item nonresponse) is more likely in information provided by proxy respondents than that obtained from the index participant (30, 43–45). Selection of the proxy respondents to be used should be based on consideration of which person would be most likely to know the facts required. Pickle et al. (44) found that the prevalence of nonresponse was generally lower for the spouse than for any other type of proxy respondents, such as siblings, offspring, and friends. Physicians can also serve as proxy respondents for medical outcomes.

Because proxy respondents are more likely to be unable to reply or to be in error than index participants are themselves (30, 43–45), it is common to reduce the

amount of information asked of proxy respondents. Often only the most important exposures and outcomes of interest are included in the proxy interview; this also reduces the burden on the proxy respondent.

### TRACING HARD TO FIND OR LOST PARTICIPANTS

Another potential source of response bias in cohort studies, in addition to bias due to participants dropping out, is failure to locate some cohort members. The only way to reduce this later source of nonresponse is through intensive efforts to locate each cohort member.

Strategies that can be used to trace participants are discussed below and summarized in table 5. Note that some of these strategies can be used in retrospective as well as prospective cohort studies. Not all approaches are available in all areas. Since multiple approaches must often be employed before the participant can be located, it is usual to pursue the simpler, least expensive approaches first, and then to resort to the more difficult or expensive approaches. With the advent of

**TABLE 5. Strategies to locate hard to find cohort members\***

- 
- Send letter to last known address with "Address Correction Requested"
  - Contact US Post Office for current address
  - Check local telephone directory for current telephone number and address
  - Check with directory assistance for current telephone number
  - Send certified letter to the participant's home
  - Consult city directories (Polk, Cole's)
  - Contact relatives and friends of member
  - Contact member's physician/medical contacts
  - Call participant's employer, if applicable and appropriate
  - For someone with an unusual last name, call others with the same last name living in the same area
  - For cohorts defined by occupation, health care source (e.g., health maintenance organization), or other source, contact the organization or appropriate professional licensing group
  - Contact current resident and/or neighbors at last known address
  - Check with landlords/rent collectors
  - If the home has been sold, contact the real estate agency for a new address
  - Check with local, state, and national registers for current address and vital status information:
    - Department of motor vehicles
    - Social Security Administration
    - State death records
    - Marriage records (for change of last name among women)
    - Voter registration records
    - Public utility or taxation records
    - Health insurance records
  - Obtain credit bureau reports (for current address only)
  - Submit search to the National Change of Address (NCOA) System
  - Submit search to National Death Index
  - Use services of a professional tracing company

Additional strategies for hard-to-reach and high-risk populations:

- Contact state welfare and other social service agencies
  - Contact treatment programs and hospitals in area
  - Contact local, state, and federal prisons
  - Contact probation, parole, coroner's, and warrant offices
  - Check with temporary employment agencies
- 

\* Listed in order of suggested implementation (from easiest to most difficulty and/or most costly to implement).

high-speed computers and the computerization of large files, even more intensive efforts, such as searching files from credit bureaus and departments of motor vehicles, have become cost-effective in recent years. For additional review and discussion of maintaining contact with and finding the whereabouts of participants of cohort studies, see Kelsey et al. (46) and Checkoway et al. (47).

Activities to locate lost or hard to find participants should continue until the participant's location and/or vital status have been ascertained, or until search strategies have been exhausted. Even if contact is not established during initial attempts, further attempts to locate the participant after several months or years may be successful. If upon reestablishing contact, the participant is no longer willing to continue as a cohort member, he/she may be willing to at least provide major outcome information at data collection points.

### Telephone contacts

Initial attempts to locate a hard to find participant usually begin with mail or telephone contacts. If the participant is employed, he/she could be contacted at work as well as at home. Among those participants not initially reachable, some will be available weeks or even months later, as would be the case with retired persons who may live elsewhere for several months during the year.

For participants whose phone number has changed, sources of new numbers include the phone book, directory assistance, or city directories which list residents by name and by street address (e.g., Cole's, Polk) (48, 49). If the participant has changed to an unlisted phone number, a supervisor from directory assistance may be willing to contact the participant and ask him/her to call the study. For someone with an unusual last name, other people who live in the same area with the same last name could be called. They may be related to the missing participant and have information on his/her whereabouts.

### Mail contacts

Early mailed attempts often consist of sending the participant a letter requesting that he/she contact the study. As with all mailings, the envelope should indicate a request for address correction. If no response is received to initial attempts and the known address is believed to be correct, a certified letter can be sent to the participant's last known address requesting that he/she contact the study.

### Personal and medical contacts

The personal contacts provided by the participant during baseline can be contacted by phone or by mail

to obtain updated address and phone number information on the participant, and to confirm that he/she is not deceased. If personal contacts cannot be reached, the participant's physician might provide this information. If these contacts are unwilling to provide the new phone number or address of the participant, they may be willing to contact the participant and have him/her call the study office. If attempts at contacting personal contacts and the physician are unsuccessful, others who might be able to provide a new address or phone number include former neighbors, the current resident at the participant's last known address (using city directories), or the real estate agency who sold the participant's home.

### The National Change of Address (NCOA) system

The US Postal Service developed the National Change of Address (NCOA) system (50) to reduce the amount of undeliverable commercial mail, and this system can be useful in tracking cohort members. All change-of-address data from almost the entire country are telecommunicated daily to a national customer support center. The resulting file (40 million changes of address annually, maintained for 3 years) is provided to licensed private companies, with updates provided every 2 weeks.

To search for lost participants, a file of current participant names and addresses is submitted to a NCOA licensee, who, for a minimum fee, will search for matches on the NCOA. If the change of address indicates an individual has moved, then a new address is provided if there is an exact match on first name, last name, middle initial, and address, whereas if the change of address indicates a household move, all that is required is a match on last name and address. As an option, however, the NCOA licensee will provide footnotes for close matches, without returning the new address, to indicate that the person might have moved. The US Postal Service estimates that 50–75 percent of moves are captured by the NCOA system. Failures are due to inexact matches, the addressee not filing a change of address with the post office, and the delay of several weeks from filing the change of address to availability on the file of the licensee.

### Other local, state, and national sources

Other state and local sources that may provide vital status or current address information include state vital statistics office and health department records, department of motor vehicles, local social security office, local voter registration records, public utility records, health insurance records, marriage records (for last name changes), and taxation records. National

sources, such as the Social Security Administration and Health Care Financing Administration (Medicare), may also be a source for updated information. For cohorts defined by occupations or other characteristics, specialized resources might be available. For example, the Nurses' Health Study uses state boards of nursing to help locate lost participants.

Credit bureaus track a fairly large proportion of US adults through national databases on loans and other financial matters. Investigators can request reports from credit bureaus on lost participants (only current address and phone number can be obtained; financial information is omitted). Large cohort studies can purchase a computer system to conduct their own searches of these databases. In addition to credit bureaus, commercial companies that specialize in tracing participants can be used.

#### **Tracing hard-to-reach and high-risk participants**

Creative and innovative strategies must often be employed when tracing hard-to-reach and high-risk segments of the population. As briefly described in table 1, the St. Louis Effort to Reduce the Spread of AIDS (ERSA) study used several innovative methods to trace intravenous drug users, such as contacting parole officers and prisons (4). Additional strategies and sources for locating cohort members from these populations include: contacting state welfare agencies; state and local social service agencies; drug treatment programs; local hospitals; federal, state, and local prisons; federal, state, and local probation and parole officers; city and county coroner and warrant offices; and temporary employment agencies. It may also be necessary to visit homeless shelters and popular neighborhood hangouts, such as bars, barbershops, pool halls, churches, and social clubs, to determine a participant's whereabouts.

#### **The National Death Index and disease registries**

Many of the large US cohort studies trace the vital status of lost participants using the National Death Index, a computer index of all deaths occurring in the United States since 1979. For a fee, the National Death Index, established by the National Center for Health Statistics, will attempt to match cohort members with their file of deceased persons (51). Patterson and Bilgrad (52) provide detailed instructions on using the National Death Index.

The basic information required for requesting searches of the National Death Index includes the participant's name and birthdate. Having additional identifiers increases the chance of a valid match and minimizes the chance of a false match being made.

These include: full name of the participant, including first name, middle initial, and last name; parents' surnames; Social Security number; date and place of birth; sex; race; marital status; last known state of residence; and age at death (estimate) or age when the participant was last known to be alive.

When any death listed in the index matches a cohort member within the specified criteria, the National Death Index provides the investigator with the date of death, the state in which the death occurred, and the death certificate number. Copies of individual death certificates from the states can then be requested by the investigator.

Several studies have found the quality of results provided by the National Death Index to be quite good (53–56). For example, Stampfer et al. (55) found that 96.5 percent of known deaths in a cohort of women were successfully matched by National Death Index; Wentworth et al. (56) reported 98.4 percent successful matches in a cohort of men. Quality improves if a Social Security number is available; a middle initial also adds to the likelihood of an accurate match. Ascertainment of full and accurate information at the beginning of the cohort study is extremely important to enhance the likelihood that a valid match will be made. When complete and accurate member data are available, the majority of those not matched by the National Death Index can be considered to be alive as of the most recent date for which the National Death Index has been updated.

Disease registries can sometimes be used to track outcomes in a cohort study. For example, the Iowa's Women's Health Study (57) ascertained cancer outcomes in the cohort by linkage to the Iowa Surveillance Epidemiology and End Results (SEER) cancer registry.

#### **Implications of tracking strategies on data analysis**

The strategies used to track vital status and disease endpoint information need to be considered in the data analysis, particularly in determining the censored time in a survival analysis. For participants without the endpoint event, the date of censoring is generally the date of death or the date last known to be alive and free of the outcome. If data on the occurrence of the endpoint are limited to information provided by the participant (or proxy), then the date of last contact would be his/her censoring date. However, if the outcome can be completely ascertained without contacting the participant (e.g., by linkage to a national disease incidence registry), then one could reasonably assume that participants without a reported outcome are free of the endpoint. This type of "passive follow-

up" means that censoring does not occur at date of last contact with each participant, but, rather, at the last date of information on the linked registry (58, 59).

An additional complexity is that for many studies, there might be only partial information on the occurrence of the endpoint or the date of endpoint, and this needs to be taken into consideration in the analysis. Passive follow-up often provides near complete, but not perfect, ascertainment of endpoints (e.g., linkage to a statewide cancer registry would provide cancer endpoints for all participants except those who have left the state). Another situation occurs when there is an indication that the event occurred but not the exact date (e.g., when incidence of cancer is the outcome of interest and death from cancer is recorded on the death certificate of a lost participant). In such cases, the researcher only knows that the incident event occurred between the time of last follow-up when the participant was free of the event and the date of death. When the progression of a condition to a defined event is the outcome (e.g., progression of human immunodeficiency virus infection to acquired immunodeficiency syndrome or of cancer incidence to death), then the researcher should obtain markers of disease progression before the outcome has occurred (e.g., CD4+ T-cell levels or cancer stage). This could provide partial information of the probability of the event if the subject is subsequently lost to follow-up (59).

## SUMMARY

The only way to ensure that losses to follow-up have not biased study results is to keep all losses to an absolute minimum. Since more complete follow-up leads to the identification of additional disease events, the effort spent in locating cohort members also improves the precision as well as the validity of the study results.

This presentation reviewed approaches for maximizing retention and minimizing loss to follow-up, including the importance of communicating the expectations of participation and collecting personal information at baseline, conducting frequent personal and mail contact, and providing incentives for participation. Response rates can be increased by repeated attempts to contact each cohort member using a range of approaches (e.g., telephone, mail, personal contacts) and by other procedures specific to mailed questionnaires, telephone interviews, or in-person visits. Lost participants can be traced by use of the NCOA system and contact with other local, state, and national sources. Finally, for those participants who are unable or unwilling to continue or who cannot be found, proxy interviews and/or use of the National Death

Index may provide information on the outcomes of interest and vital status.

Additional research evaluating the efficacy of the various approaches to retention and tracking is needed to help investigators learn how to best apply study resources to retain and keep track of the largest possible number of cohort members.

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